Tribal Leaders Diabetes Committee

Meeting Summary

August 10–11, 2005
Washington, DC

(Approved November 9, 2005)

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Contents

TLDC Members Present:

Cathy Abramson (Bemidji Area)

Dr. Kelly Acton (Federal co-chair)

Jerry Freddie (Navajo Area; Day Two only)

*Arlette Hagar (Aberdeen Area)

Linda Holt (Portland Area)

Rosemary Nelson (California Area)

Buford Rolin (Tribal co-chair; Nashville Area)

H. Sally Smith (Alaska Area)

*Phil Swain (Phoenix Area)

* Mr. Swain and Ms. Hagar were asked to represent their respective Areas; however, they have not been officially appointed as alternates to the TLDC.

Excused TLDC Members:

Dr. Judy Goforth Parker (Oklahoma Area)

Others in Attendance:

Dr. Larry Agodoa	Stacy Bohlen	Ann Marie Bosma
Elaine Dado	Dr. Lemyra DeBruyn	Carolee Dodge Francis
Dr. Sandy Garfield	Rhonda Harjo	Dr. Thomas Hertz
Candace Jones	Alida Montiel	Dr. Kelly Moore
Diddy Nelson	Anthia Nickerson	Leo Nolan
Marie Osceola-Branch	Dr. Jon Perez (by phone)	Patricia Pittman
Travis Platero	Lynn Provost	Dr. Steve Rith-Najarian
Dr. Yvette Roubideaux	Dee Sabattus	Dr. Bernadine Tolbert
Althea Tortalita Cajero		

Frequently Used Abbreviations:

ADA ..... American Diabetes Association

AI/AN..... American Indian and Alaska Native

CDC.....Centers for Disease Control and Prevention

DETS..... Diabetes-based Science Education in Tribal Schools

DDTP .....Division of Diabetes Treatment and Prevention

Frequently Used Abbreviations (continued)

GPRA ..... Government Performance and Results Act
GUI..... graphical user interface
IHCIA..... Indian Health Care Improvement Act
IHS ..... Indian Health Service
IRB ..... Institutional Review Board
IT..... information technology
MOU ..... Memorandum of Understanding
NCAI ..... National Congress of American Indians
NCUIH ..... National Council of Urban Indian Health
NDWP ..... Native Diabetes Wellness Program
NIDDK ..... National Institute of Diabetes and Digestive and Kidney Diseases
NIH..... National Institutes of Health
NIHB ..... National Indian Health Board
RFA ..... Request for Application
RPMS ..... Resource and Patient Management System
SDPI ..... Special Diabetes Program for Indians
TLDC ..... Tribal Leaders Diabetes Committee
TSGAC..... Tribal Self-Governance Advisory Committee

Summary of TLDC Motions:

- TLDC meeting summaries from February 10–11, 2005, and May 12–13, 2005, were approved (page 21).
- TLDC charter was approved (page 22).

Summary of TLDC Meeting Action Items:

- The TLDC recommends that Dr. Roubideaux review the Competitive Grant Program IRB training materials with them at a future meeting (page 8).
- The TLDC will continue the discussion of the Competitive Grant Program evaluation and participant protection plan during the next TLDC meeting. The TLDC would also like an update on the final planning meeting (page 9).
- The TLDC will need to discuss the U.S./Mexico roundtable and submit their suggestions to Leo Nolan (page 14).
- The TLDC will strike sections 10 and 11 from the charter (pages 15 and 21).

- The TLDC will separate NCAI and NIHB into two bullets under membership composition in the charter (page 15).
- The TLDC will present the charter to Dr. Grim in the form of a letter, rather than a circular (page 15).
- Mr. Rolin and Dr. Acton will submit a draft of the charter letter to TLDC members (page 15).
- The TLDC will provide direction to the new member organizations on appointing representatives and alternates (page 15).
- The TLDC will consider sending correspondence to alternates as part of their policies and procedures (page 15).
- Dr. Acton will provide the DHHS Division of Grants Operations final report on the SDPI to the TLDC (page 17).
- The IHS DDTP and the NIHB will explore the possibility of adding a TLDC page to the NIHB website (page 19).
- The NIHB will develop a summary of helpful websites for Tribal leaders and their staff (page 19).
- The IHS DDTP will explore developing a DVD that summarizes the *SDPI Report to Congress* (page 19).
- The IHS DDTP and the NIHB will provide copies of all presentations at future TLDC meetings (page 19).
- The NIHB will develop policies and procedures for the TLDC prior to the November meeting (page 21).
- The TLDC recommended that the IHCIA include language that each Area is required to have an Area diabetes consultant (page. 22).

Tribal Leaders Diabetes Committee Meeting

Day 1: August 1, 2005

Subject	Discussion	Action
Welcome and Introductions	**Day One—Wednesday, August 10, 2005** **Mr. Buford Rolin, Tribal co-chair, called the meeting to order at 9:00 a.m.** Mr. Rolin: – Welcomed TLDC members and guests to the meeting and delivered the opening prayer. – Asked Althea Tortalita Cajero to conduct the roll call for TLDC members. – Asked TLDC members and guests to introduce themselves. – Noted that a quorum had not been met, but was expected for Day Two of the meeting. – Reviewed the meeting agenda.	Transcript Cross-reference: Pages 6–7
Update on the SDPI Competitive Grant Program Background TLDC and Tribal consultation	Dr. Yvette Roubideaux is a member of the Rosebud Sioux Tribe. She currently is on the faculty of the University of Arizona at Tucson and co-director of the Coordinating Center for the SDPI Competitive Grant Program. She provided an update on the program. Background and purpose of the SDPI Competitive Grant Program: – The SDPI Competitive Grant Program was established through the $50 million increase per year that Congress gave the SDPI from 2004 through 2008. – Congressional direction on the Competitive Grant Program said that the increase in funds must be spent on two things: (1) improving the quality of the data and the evaluation around the SDPI; and (2) establishing the Competitive Grant Program. – The purpose of the Competitive Grant Program is to implement activities in one of two areas: (1) diabetes prevention; and (2) cardiovascular disease risk reduction, which is the most compelling complication of diabetes. – Congress instructed the IHS to distribute the grants through a competitive process (i.e., Indian health programs needed to compete for the funding) and to evaluate this initiative. TLDC and Tribal consultation: – The IHS conducted TLDC and Tribal consultation to determine how the Competitive Grant Program funds would be spent. – Following Tribal consultation, the TLDC developed the following recommendations for the program: (1) current SDPI programs would be	Transcript Cross-reference: Pages 8–18

Subject	Discussion	Action
TLDC and Tribal consultation (continued)	the only eligible applicants; (2) a diverse group of grantees should be selected to ensure representation based on size of program, type of program (i.e., IHS, Tribal, and urban programs), and geography; and (3) the program must be well coordinated and well evaluated. – Based on TLDC recommendations and Tribal consultation, the IHS Director Dr. Grim decided that $27.4 million out of the $50 million increase would go to the Competitive Grant Program.	
Grant application process	Grant application process: – The RFA went out in May 2004, and applications were due July 1, 2004. – 128 out of the 300 SDPI programs applied for the grants. – In August 2004, the IHS conducted an internal review of the applications, and then invited an external review committee to review the applications in a formal and fair process. – During the review process, each application was scored based on how well it responded to the RFA. At the end of the review, the IHS DDTP selected the higher scoring applications while also ensuring good Area, size, and program representation. – Of the 128 applicants, 66 programs were funded. 36 programs were funded for the diabetes prevention initiative, and 30 programs were funded in the cardiovascular disease risk reduction initiative. – In September 2004, the grantees received their notice of grant awards, as well as further direction on the scope of work and terms and conditions of their grant. All grantees agreed to the scope of work and terms and conditions, and revised their budgets to meet the requirements of this initiative. Each grantee received $300,000–400,000 per year.	
Competitive Grant Program timeline	Competitive Grant Program timeline: – The first year, which has been devoted to planning project activities through face-to-face meetings with the grantees, started in October 2004. The grantees are using a collaborative process to share their experiences, make recommendations, and decide how they will implement the required project activities. The planning year is also devoted to tasks such as orienting the grantees, setting up ways to communicate, preparing for data collection, providing participant protection and IRB training, obtaining IRB approvals, purchasing necessary equipment, and hiring staff. – The second, third, and fourth years of this five-year initiative will involve project implementation: three years of diabetes prevention and intensive case-management to reduce risk for cardiovascular disease. – The fifth year will most likely be devoted to training and dissemination of lessons learned.	
Training and technical assistance	Training and technical assistance: – Diabetes prevention project: Training and technical assistance has	

Subject	Discussion	Action
Training and technical assistance (continued)	included trainings on how to teach the DPP curriculum. – Cardiovascular disease risk reduction project: Training and technical assistance has included current standards for reducing blood pressure and cholesterol, smoking cessation, and reducing blood sugars. – The Coordinating Center has also provided technical assistance to grantees that have had difficulty getting started.	
Project activities	Project activities: – Diabetes prevention project: Screen and recruit people with prediabetes at community events or in clinics, implement the 16-session DPP curriculum, and follow-up with participants on a monthly basis. – Cardiovascular disease risk reduction project: Recruit people with diabetes to come to the clinic once a month to receive intensive case management.	
Participant protection and IRB approvals	Participant protection and IRB approvals – Every grantee must obtain approval from their local IRBs. – The Coordinating Center is obtaining approvals from the IHS National IRB and the IHS Area IRBs. – All data stay at the grantee sites and are protected locally. When the data are sent to the Coordinating Center, all identifiers are removed; all names, addresses, social security numbers, chart numbers, birth dates, and other identifiable data are removed. In addition, names of Tribes are removed from the data when they are sent to the Coordinating Center. All project data will be kept locally in a locked file cabinet to which only one person has the key. – The sixth and final planning meeting will include training on participant protection. The TLDC recommended that the training materials be shared with the TLDC.	The TLDC recommends that Dr. Roubideaux review the Competitive Grant Program participant protection training materials with them at a future meeting.
Evaluation	Evaluation – Congressional direction and TLDC recommendation were that the evaluation must show Congress that the funds were spent well. – The grantees are developing the evaluation through a collaborative process with the Coordinating Center during the planning year. – Possible questions that the evaluation will need to address include: Did the programs actually implement the activities, what were the challenges and lessons learned, what were the things that made people or programs successful, did quality of care improve, diabetes or cardiovascular disease prevented, were the improvements were really due to the activities of the Competitive Grant Program and not due to the non-competitive SDPI programs?	
Concerns from TLDC members regarding the evaluation	– Ms. Holt and other TLDC members raised concern about teasing apart the effects of the competitive and non-competitive SDPI programs. Many of the competitive grantees are receiving assistance and support	

Subject	Discussion	Action
Concerns from TLDC members regarding the evaluation (continued)	from their non-competitive programs. They also voiced concern that Congress may view good outcomes as the result of competitiveness. Dr. Acton said that the evaluation might try to answer the question, were you effective in truly making a difference *beyond* what was already being done in the communities? Dr. Roubideaux noted that it would be important to show that good outcomes were the result of more intensive, specific activities—not competitiveness. – TLDC members asked about whether beneficial information would be disseminated to Tribes immediately. Dr. Roubideaux explained that the Coordinating Center has established a Dissemination Core, which is charged with the responsibility of sharing information on the initiative. The IHS DDTP plans to include some of the trainings that the competitive grantees have received during the upcoming regional meetings for all SDPI grantees. The Coordinating Center also plans to establish a website and newsletter on initiative activities.	
Change in funding amounts	Change in funding amounts: – Dr. Acton reported that the IHS DDTP originally agreed to fund 65 programs. One applicant, who was originally denied a grant, appealed the decision. The IHS DDTP realized that an administrative error had been made in the IHS DDTP. After a second independent review, the applicant was awarded a grant. – After the appeal, a total of 66 programs were funded. As a result, the small programs received $4,000 more than they should have for the first year of the initiative; the large programs received $6,000 more than they should have for the first year (i.e., over the next four years of the initiative, the small programs will receive $4,000 less than the first year, and the large programs will receive $6,000 less).	
Discussion with TLDC members	Discussion with TLDC members: – Ms Holt noted that childhood obesity is an important issue that needs to be addressed. – Ms. Smith noted that Congress might want to address the issue of health care costs, particularly because of the rapidly aging population, the increasing population of youth, chronic diseases, and increasing focus on prevention. She felt that they would want to know how Indian programs utilized special set-aside funds to interface with other ongoing national programs, such as the chronic disease policy academies with the National Governors Association. – Mr. Rolin noted that Congress would want to know that the grantees listened to the concerns of the nation and the Tribes and have taken actions to address them. – Mr. Swain noted that Congress would want to know if the program made a difference. The TLDC discussed whether answering this question would move the program evaluation into the field of research. Mr. Swain felt that it would be important to conduct a comparison study	

Subject	Discussion	Action
Discussion with TLDC members (continued)	to see if this program makes a positive difference in the health of AI/AN people. Ms. Nelson concurred and suggested that the Competitive Grant Program be compared to programs that did not receive the funds. – Ms. Nelson noted that more funding is needed to train and educate programs that did not receive competitive grant funds on how to implement intensive diabetes prevention and cardiovascular disease risk reduction activities. – Ms. Holt suggested that the discussion on the evaluation and participant protection be included on the next TLDC meeting agenda. She would like the Competitive Grant Program to provide an update on what was decided during the final planning meeting.	The TLDC would like to continue the discussion of the Competitive Grant Program evaluation and participant protection plan during the next TLDC meeting. The TLDC would also like an update on what was decided during the final planning meeting.
Overview and Discussion of the IHS Director's Initiatives Behavioral health initiative	The Indian health system has made significant progress in decreasing the mortality rates for tuberculosis, infant deaths, maternal deaths, and accidents over the past 50 years. However, AI/ANs still suffer from significant health disparities in cardiovascular disease, diabetes, accidents, suicides, and deaths related to alcohol. Based on these issues, Dr. Grim recently announced that the IHS would focus on three health initiatives: (1) behavioral health; (2) chronic disease; and (3) health promotion and disease prevention. Information on all three initiatives can be found at the following website: http://www.ihs.gov/NonMedicalPrograms/DirInitiatives/index.cfm Dr. Perez presented the behavioral health initiative: – The programs of the Division of Behavioral Health are divided into four broad areas: (1) direct service support, such as the suicide collaborative and children's programs; (2) data; (3) training; and (4) collaboration. – Specific activities of the Division of Behavioral Health include: ▪ The initiative to bring data systems up to national standards and beyond. The data system can document contacts and effectiveness across a wide range of clinical information. ▪ The IHS Suicide Prevention Initiative. This initiative was established in 2003 to address suicide prevention in a coherent manner and provide training on suicide prevention in each Area. ▪ The IHS–Health Canada MOU. The little data that exist on suicides in Indian Country indicates very different patterns of suicidal behavior for AI/ANs as compared with the general population. The MOU, signed in 2003, paved the way for the IHS to establish a working group with members from the IHS, National Institutes of Mental Health, Health Canada, and Native Institute of Health Research. The goal of the working group is to increase the level of research in Indian Country, examine effective programs, and develop specific practice models. ▪ Suicide reporting form. These forms are confidential (i.e., all identifiable information is all removed) and are reported to the	Transcript Cross-reference: Pages 18–29

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Behavioral health initiative (continued)	national database to research the causes and correlates to suicidal behavior. ▪ Rewrites of chapters for clinical care. ▪ Behavioral health GUI for RPMS and the integrated behavioral health electronic health record. – The behavioral health initiative will continue to focus on three basic areas: (1) continued use of data and data driven programs to evaluate effectiveness; (2) supporting direct service for Tribally operated programs; and (3) developing leadership of these programs.	
Chronic disease initiative	Dr. Rith-Najarian presented the chronic disease initiative:	
Metabolic syndrome	– Metabolic syndrome is a root cause of many chronic diseases. It is a very common condition that is associated with the weight carried around the waist. This weight is metabolically active and secretes a range of substances that create inflammation, influence clotting, promote tumor growth, and regulate appetite and insulin resistance. – Metabolic syndrome starts with risk factors, such as hereditary factors, lifestyle, nutrition as you develop in the womb, and early nutrition and breastfeeding practices. During the first to third decades of life, weight gain develops, which is associated with insulin resistance. After 5–10 years, prediabetes develops. Approximately five years later, if the patient does nothing, diabetes can develop. Another ten years later, if the diabetes is not aggressively managed, people will develop eye and nerve and kidney damage. – Conditions associated with metabolic syndrome are diabetes, heart disease, endocrine problems, fatty deposits in the liver, asthma, cholesterol gallstones, sleep apnea, and cancer. The Strong Heart Study showed that people with metabolic syndrome were at twice the risk for developing diabetes.	
Clinical guidelines for metabolic syndrome and prediabetes	– To address the problem of metabolic syndrome, the IHS DDTP convened a task force last year to develop clinical practice guidelines to treat prediabetes and metabolic syndrome. The three main goals of the guidelines are: (1) identify people with prediabetes and metabolic syndrome through screening protocols, and then track and code for it; (2) among those with prediabetes and metabolic syndrome, work aggressively to prevent diabetes; and (3) reduce the risk of cardiovascular disease by controlling blood pressure and lipids, smoking cessation, and anti-platelet therapy. The screening recommendations for prediabetes and metabolic syndrome are similar to the ADA recommendations for screening for diabetes except that the taskforce lowered the screening age to 18 if the person has risk factors. If a person does not have risk factors, they recommend screening at age 35.	
Chronic Care Model	– The Chronic Care Model developed by Dr. Ed Wagner with Group Health Cooperative outlines the six components of care that collectively make a substantive difference in improving chronic illness. These six	

Subject	Discussion	Action
Chronic Care Model (continued)	components include: (1) self-management support (e.g., skills, social support, and education for patients); (2) delivery system design (e.g., case managers, clear lines of communication, and tracking systems); (3) decision support (e.g., clear clinical guidelines, consultation, training on guidelines, and feedback); (4) information systems (e.g., RPMS, registries, health summaries, and reminder systems); (5) support from leadership; (6) support from the community. As a result, informed and active patients will have productive interactions with prepared practice teams, leading to improved clinical outcomes. – The chronic care initiative will include rolling out the Chronic Care Model in the Indian health system. First, this will involve raising awareness of the model by introducing it to Tribal leadership, the NIHB, and Area directors at the National Council meeting in February 2006 and during regional conferences. Second, IT support will be increased to describe components of the Chronic Care Model in health summaries to provide decision support. Third, the model will be adapted to current programs through activities such as the diabetes best practice models. Finally, the IHS plans to pilot a Chronic Care Model Collaborative. – Dr. Acton noted that Ms. Holt and Ms. Smith are the TLDC representatives on the chronic care initiative workgroup.	
Health promotion and disease prevention initiative	Ms. Jones presented the health promotion and disease prevention initiative: – The goal of the health promotion and disease prevention initiative is to create healthier individuals, families, and communities by building infrastructure, increasing community capacity, enhancing partnerships, expanding resources, and focusing on evaluation. – The IHS has hired a national health promotion and disease prevention coordinator, as well as coordinators in nine of the twelve IHS Areas. – The IHS established the Policy Advisory Committee to engage Tribal leadership and provide oversight and policy guidance to the agency. The committee includes representatives from the NCAI, NIHB, CDC, NCUIH, TSGAC, direct service Tribes, and IHS. – The Policy Advisory Committee is developing a strategic plan that will focus on four areas: (1) school policies for physical activity, school food services, vending machines, and competitive food sales; (2) marketing plans to increase people's awareness of why it is important to prevent diseases; (3) community involvement; and (4) partnerships. – The IHS established the Prevention Taskforce, whose members support the Policy Advisory Committee with leadership from Dr. Chris Percy at the Shiprock service unit. The Taskforce works to identify best practices, identify training needs, promote and support school and workplace policies, and develop evaluation processes. – The IHS developed the Healthy Native Communities Fellowship to engage people at the community level and share their lessons learned. – The IHS established the Community Champion Forums to bring people	

Subject	Discussion	Action
Health promotion and disease prevention initiative (continued)	together, share what is working in the communities, and facilitate networking opportunities. – The IHS has formed partnerships with the Just Move It Program and Nike, National Boys and Girls Club, CJ Foundation, and United National Indian Tribal Youth. – Other activities include a competitive grant program, improving information access (e.g., best practices for clinics and communities, resources, community assessment tools, and training and grant opportunities on the initiative's website), and working with communities to develop community health profiles. – Evaluation for this initiative includes GPRA indicators, RPMS data, community health assessments, and behavioral risk surveys. **Break**	
Development of a U.S./Mexico Roundtable on Type 2 Diabetes in Indigenous Populations	**Meeting called to order at 1: 20 p.m.** Mr. Nolan from the IHS, Dr. Hertz from the DHHS, and Ms. Pittman from Academy Health met with the TLDC to obtain their input on the U.S./Mexico roundtable on type 2 diabetes in indigenous populations: – The Security and Prosperity Partnership of North America, which was signed by Paul Martin, Prime Minister of Canada; Vicente Fox, President of Mexico; and President Bush in March 2005, states that the three countries will work to, "Improve the health of indigenous people through targeted bilateral and/or trilateral activities, including health promotion, health education, disease prevention, and research". The U.S./Mexico roundtable is a result of this agreement. – Dr. Hertz provided an update on the activities of the DHHS Office of Planning and Evaluation. Michael O'Grady, assistant secretary for Planning and Evaluation, has had a long-standing interest in AI/AN activities. He spearheaded efforts to encourage department-wide research collaboration with the IHS. His other activities have included transferring money from his portfolio to the IHS to allow the EpiCenters to look at best practices on cardiovascular research, examining the administrative and programmatic barriers to grants for which Tribes are eligible, and exploring the formation of a Tribal advisory group that could advise the DHHS on priorities for research. – Academy Health recently notified Mr. O'Grady that the Mexican government had expressed an interest in preventing diabetes in indigenous populations and were interested in meeting their counterparts in the U.S. to share ideas and data. The roundtable would provide an opportunity for two-way learning between the two countries. – Possible agenda topics include epidemiology and research, prevention practices, nutrition, health promotion, and culturally appropriate care.	Transcript Cross-reference: Pages 30–39

Subject	Discussion	Action
U.S./Mexico Roundtable on Type 2 Diabetes in Indigenous Populations (continued)	– The parameters for the roundtable include: (1) the meeting will be small with approximately 25 participants (12–13 participants from the U.S. and 12–13 participants from Mexico); (2) Mexican, U.S., and Tribal representatives will be at the meeting; (3) the meeting will be a one and a half day meeting tentatively scheduled for December 2005 to be held in Mexico; and (4) the DHHS and Academy Health will prepare two or three issue papers for both the U.S. and Mexico, which may be based on the *SDPI Report to Congress* and diabetes best practice models. – The Office of Evaluation and Planning has met with the CDC, NIH, Office of Local Health, and Office of Intergovernmental Affairs. The Office of Intergovernmental Affairs suggested that the DHHS meet with the TLDC, NIHB, TSGAC, Inter Tribal Council of Arizona, and others to obtain input. They also suggested that the DHHS immediately send a letter to all Tribes regarding the roundtable and ask for input. – The DHHS would like TLDC input on potential meeting participants, agenda topics, contacts in Mexico, and issue paper topics.	
Discussion with TLDC members and audience	Discussion with TLDC members and audience: – Ms. Montiel asked if meeting participants would be restricted to Tribes close to the U.S./Mexico border. Dr. Hertz responded that meeting participation will not be based on geography. – Ms. Montiel suggested that the DHHS learn more about the CDC activities along the U.S./Mexico border, including their trilingual focus groups on health issues with Tohono O'odham members living south of the U.S.–Mexico border and health fairs. – Mr. Nolan noted that it is important to recognize the different relationship that the indigenous population in Mexico has with the Mexican government as compared with the U.S–Tribal relationship. – Mr. Swain voiced concern about ensuring that the health of AI/ANs are a priority, the problems associated with illegal immigrants crossing the border, and the need for expanded Indian hiring preference. Ms. Provost agreed with Mr. Swain's comments about the need for more support and funds for Indian health programs. – Ms. Montiel noted that the Native Seeds/SEARCH in Tucson has many contacts with indigenous communities in Mexico and would be a good resource for input and ideas on the roundtable. – Dr. Acton asked Dr. Hertz to facilitate health research on translation and effectiveness for AI/AN communities. Dr. Hertz responded that he needs specific research ideas that he can pass on to the NIH and CDC. – Dr. Hertz encouraged the TLDC members to contact him to provide specific input on the roundtable. Mr. Rolin noted that the TLDC will continue discussing the roundtable and submit their suggestions. **Break**	TLDC will need to discuss the U.S./Mexico roundtable and submit their suggestions

Subject	Discussion	Action
Development of the TLDC Charter	**Meeting called to order at 2:53 p.m.** Mr. Rolin facilitated discussion of the TLDC charter: – Mr. Rolin updated the committee on a meeting with Dr. Acton, Ms. Smith, Mr. Rolin, and Dr. Grim in May 2005 to follow-up on the remaining issues of the TLDC charter. Dr. Grim agreed with the recommendations of the TLDC regarding membership rotation. – During the meeting, Dr. Grim maintained the following: (1) the committee will become a 17-member committee with the addition of five new members from national organizations; (2) the federal co-chair will be a voting member of the TLDC; and (3) each Area and organization must appoint a representative and an alternate, one of whom must attend the meeting as standard procedure. – Ms. Smith suggested that a quorum should be determined by Area representation. Ms. Holt agreed with this suggestion. – Mr. Swain suggested that the charter outline the process for proxy voting in the event that both the representative and alternate are unable to attend. Dr. Acton suggested that the charter could say that either the Area director of the Area TLDC representative would appoint a proxy by letter. Ms. Dado said that the letter would become part of the records for the TLDC meetings. – Mr. Swain suggested that the charter outline the process in the event that the representative has a certain number of unexcused absences. – Ms. Hagar suggested that all TLDC correspondence go to alternates as well as representatives. Ms. Holt agreed with the suggestion. – Mr. Rolin suggested that the charter be presented to Dr. Grim in the form of a letter (not in a circular format). The NIHB will prepare a final draft of the charter in letter format and send it to the TLDC. – The TLDC discussed the status of the MOU with the NIHB. Ms. Dado noted that funds from Rocky Boy have been transferred to the NIHB. Dr. Acton noted that the IHS DDTP incurs expenses and will hold $50,000 from the TLDC budget for those expenses. However, the IHS DDTP will request the ability to transfer up to $150,000 to the NIHB. – Mr. Rolin suggested that section #10 be struck from the charter and that the NCAI and NIHB under membership composition should be separated into two bullets. – Mr. Rolin noted that the name of the TLDC will not change once the charter takes effect. He also noted that the TLDC will need to provide the new member organizations with information on TLDC procedures on appointing representatives and alternates. **Meeting recessed at 4:15 p.m. until 9:00 a.m. August 11, 2005.**	Transcript Cross-reference: Pages 39–46 The TLDC should consider sending correspondence to the alternates The TLDC charter will be presented to Dr. Grim in the form of a letter, rather than a circular Strike the section #10 on the effective date Under membership composition, separate NCAI and NIHB into two bullets A draft of the charter letter will be sent to the TLDC TLDC will need to give direction to the new member organizations about the procedure for appointments

Tribal Leaders Diabetes Committee Meeting

Day 2: August 11, 2005

Subject	Discussion	Action
Welcome	**Day Two—Thursday, August 11, 2005** **Meeting called to order at 9:06 a.m.** – Welcome by Buford Rolin, TLDC Tribal co-chair – Prayer by Jerry Freddie, representative from the Navajo Area – Eight representatives or alternates were in attendance	Transcript Cross-Reference: Page 47
IHS DDTP Update Diabetes epidemic Background on the SDPI Annual distribution of SDPI funds	Dr. Kelly Acton provided an update of the IHS DDTP: Epidemic of diabetes: – AI/ANs have the highest rates of diabetes across all age groups, for both men and women, and across all ethnic groups. – From 1990 to 2002, the prevalence of diabetes increased 132% in 25–34 year olds, and increased 106% in 15–19 year olds. Background on the SDPI: – The SDPI started in 1997 with the Balanced Budget Act. Congress gave us $30 million per year for five years through 2002. The original SDPI legislation said that the funds were to be used for prevention and treatment of diabetes through a grants process, and that the IHS was required to conduct an evaluation of the program. – In 2001, the Consolidated Appropriations Act increased that amount of SDPI funds by $70 million. Starting in 2001, the SDPI received $100 million per year. Congress provided more direction, saying that the SDPI was to use a best practices approach to build upon lessons learned and to use partners like the CDC and NIH. – For the 2004 budget, Congress continued SDPI funding through 2008 and increased the funding by $50 million per year. Congress gave specific instructions to: (1) maintain the current grant program; (2) strengthen the IHS data infrastructure; and (3) implement a Competitive Grant Program on the primary prevention of diabetes and the most compelling complication of diabetes, which is cardiovascular disease. – To summarize, the SDPI started in 1998 with $30 million per year, and now receives $150 million per year through 2008. Annual distribution of SDPI funds (Total = $150 million per year) – $108.9 million to the Areas by formula for the non-competitive grants. – $5.2 million to strengthen the data infrastructure and contribute to the electronic health record effort. Half of these funds go to the Areas, and	Transcript Cross-Reference: Pages 47–56

Subject	Discussion	Action
	the other half remains at Headquarters. – $27.4 million to the Competitive Grant Program. – $7.5 million to urban health programs. – $1 million to the CDC NDWP.	
Renewal applications for the SDPI	Renewal applications for the SDPI: – The competitive grant program includes 66 grantees. Their first annual renewal applications will be reviewed in August 2005. Notices of grant award will go out at the end of September. In October, the grantees will begin recruiting patients and implementing project activities. – The non-competitive grant program currently includes 318 grantees. 81% of the grantees are Tribally run, 10% are urban, and 9% are IHS. The non-competitive grants are reviewed on four cycles throughout the year by the Area diabetes consultants or the chief medical officers. – The IHS DDTP is working with the IHS Division of Grants Operations on carryover policy. The SDPI has legislative authority to carry funds over. When a grantee has a substantial amount of carryover, the IHS Division of Grants Operations, works with each grantee individually. Very few grantees have a substantial amount of carryover.	
DHHS review of SDPI	DHHS review of the SDPI: – The Office of Inspector General elected not to review the SDPI because the DHHS Division of Grants Operations will conduct a review. – At the end of July, the IHS DDTP met with the DHHS grants reviewers to explain the SDPI processes and procedures. – Dr. Acton will provide the TLDC with a copy of the final report when it becomes available.	Dr. Acton will provide the TLDC with a copy of the DHHS Division of Grants Operations final report on the SDPI
Data funds	Data funds: – $2.6 million goes to the Areas to support electronic health record activities. Areas can use these funds to buy hardware, load software, or hire or contract with people who can get the electronic health record up and running. If an Area did not use the funds for electronic health record activities, the amount of future funding will be reduced. – The IHS is still waiting for data plans for 2006 from most Areas. Nine out of twelve Areas have submitted reports on how the funds were used during the past year. The IHS DDTP tracks these funds, but transfers them to the IHS Office of Information Technology for administration. No funds will be distributed until the IHS receives a plan from each Area on how they will address the electronic health record. – $2.6 million stays at Headquarters for national data activities. The funds are used for software development, such as the Patient Information Management System, as well as the National Data Warehouse and DataMarts. The IHS DDTP plans to have the Diabetes DataMarts available this fall. The funds are also used to support the	

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	electronic health record, RPMS integrated case management programming, and web-based audit reporting. The web-based audit is ready, but needs to be tested. It will be ready for use next year.	
SDPI Report to Congress	*SDPI Report to Congress*: – The report took one year to get approval from the DHHS, but it is now printed and available on the IHS DDTP website. – The report summarizes the SPDI non-competitive grant program and diabetes in the AI/AN population.	
Diabetes network	Diabetes network: – The IHS DDTP office in Albuquerque includes four professional staff and a support staff. The IHS DDTP will hire a deputy and administrative officer, as well as two project officers to oversee the Competitive Grant Program. The IHS Nutrition and Dietetics Training Center will administer contracts for the IHS DDTP. – The network also includes 13 Area diabetes consultants, 19 Model Diabetes Programs around the country at 23 different sites, and 399 non-competitive and competitive grantees.	
Training and technical assistance	Training and technical assistance: – In 2004, the IHS DDTP held four regional meetings around the country to help the grantees apply for the Competitive Grant Program. The regional meetings provided grantees with the opportunity to share information with one another and to obtain information, training, and technical assistance from the IHS DDTP. – In the summer of 2005, the IHS DDTP held summer institutes in partnership with Oregon Health Sciences University in Portland, Oregon, and the University of New Mexico in Albuquerque, New Mexico. The summer institutes were intensive, content-based training sessions on areas, such as RPMS and software packages, motivational interviewing, and behavior change. – Feedback from the attendees of the regional meetings and summer institutes was that the grantees want these training sessions again. The IHS DDTP plans to combine the regional meetings and the summer institutes next year. The regional meetings and summer institutes will also include technical assistance and training from the Competitive Grant Program Coordinating Center.	
Web-based activities	Web-based activities: – The IHS DDTP is exploring web-based training activities and is building a listserv of non-competitive grantees. – The IHS DDTP plans to send e-newsletters and bulletins to keep grantees up to date.	
Discussion with TLDC members	Discussion with TLDC members: – Mr. Swain requested that the IHS provide information on the	

Subject	Discussion	Action
Discussion with TLDC members (continued)	breakdown of funds allocation by Area. The TLDC discussed the possibility of having a TLDC section on the NIHB website where Tribal leaders could refer for information. – Ms. Abramson requested a summary of helpful websites for Tribal leaders and their staff. The NIHB will prepare this summary. – Mr. Freddie requested that the IHS DDTP develop audiovisual materials, such as a DVD that summarizes the *SDPI Report to Congress*. The IHS DDTP will explore this possibility. – Ms. Holt requested that the IHS DDTP provide copies of all PowerPoint presentations made during TLDC meetings to TLDC members. The IHS DDTP will ensure that all presentations are distributed to TLDC members at the end of each meeting. – Several TLDC members voiced concern about ensuring that the *SDPI Report to Congress* is used effectively and disseminated widely. The IHS DDTP explained that the Hill Group is developing one-pagers that summarize the contents of the report. The ADA also plans to host a luncheon for the Congressional Diabetes Caucus to present the report.	IHS DDTP will explore the possibility of adding a TLDC page to the NIHB website NIHB will develop a summary of helpful websites for Tribal leaders and their staff IHS DDTP will explore developing a DVD that summarizes the *SDPI Report to Congress* IHS DDTP and NIHB will provide copies of all presentations at future TLDC meetings
Update on the DETS Program Background on the DETS Program DETS curriculum goals	Dr. Moore from the IHS DDTP, Dr. Agadoa from the NIH, Dr. Garfield from the NIH, Dr. DeBruyn from the CDC, and Ms. Dodge Francis from the CDC provided an update on the DETS Program for the TLDC Background on the DETS Program: – In 1999, the NIDDK invited the TLDC to initiate a collaboration with the NIH and the NIDDK and discuss what the TLDC thought were the contributions that the NIH could make to AI/AN communities. – The major recommendation was that there are not enough AI/AN researchers, physicians, and health care workers. – Based on that recommendation, the NIDDK developed the DETS Program and invited Tribal colleges to help develop a curriculum. NIH has funded the program, with co-funding from the IHS and CDC. – The DETS Program is a project to develop a K–grade 12 curriculum with a multidisciplinary approach (i.e., focus includes biomedical science, as well as subjects like social science and art). Its purpose is to develop and implement a school-based diabetes curriculum to support the integration of AI/AN culture and community knowledge with diabetes related science. The curriculum also aims to help change mindset of how AI/ANs think about diabetes and diabetes prevention. – The curriculum incorporates all national education standards. DETS curriculum goals: – The first goal of the curriculum is to increase the understanding of health, diabetes, and how to maintain balance in AI/AN children, their families, and their communities. Each goal includes issues of	Transcript Cross-Reference: Pages 56–65

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DETS curriculum goals (continued)	understanding or take-home messages. An issue of understanding for goal one is that diabetes is an imbalance of health at many levels. – The second goal is to increase students' understanding and appreciation of how scientific information is developed and how community knowledge affects it and contributes to it. – The third goal is to improve interest in entering health professions.	
DETS curriculum timeline	DETS curriculum timeline: – Curriculum development started in September 2002. The curriculum development is now complete, and schools in proximity to the Tribal colleges have been selected to do pilot testing. Following the pilot testing, the curriculum will be improved and then beta tested. – To ensure that the curriculum is representative of all regions, the DETS Program is currently looking for eight more schools to participate. These schools will be paired with a Tribal college for support and assistance. The DETS Program is looking for schools that are in regions that do not have a Tribal college. TLDC members suggested that the DETS Program make presentations to Area health boards and work with the Office of Indian Education Programs and the National Indian Education Association. – Final implementation and dissemination of the curriculum throughout Indian Country will start in 2008.	
Discussion with TLDC members	Discussion with TLDC members and audience: – Ms. Montiel raised concern about whether the curriculum would be easy for teachers to adapt. The DETS Program responded that one purpose of the beta testing is to determine curriculum adaptability. – Ms. Abramson voiced concern about whether teachers would have enough time to learn a new curriculum and fit it into their class schedule. The DETS Program responded that the majority of the curriculum, except the social studies and English lessons, are based on the national science standards. The teacher can use the curriculum and cover the same material that national and state standards require. – Ms. Bosma noted that an important marketing message for the curriculum is that it is interesting, promotes active learning, and will make the teachers' lives easier. – Dr. Tolbert noted that the curriculum should include introducing AI/AN students to AI/AN health care professionals. – Ms. Smith noted that she would like to see that the TLDC continue providing guidance and oversight to the DETS Program. Dr. Acton suggested that once NIH completes testing of the curriculum and it is ready for dissemination, the IHS and TLDC will provide oversight; however, the IHS might consider contracting with an educational organization to aid in the dissemination of the curriculum.	

Subject	Discussion	Action
Review of Minutes from February and May 2005 TLDC Meetings Motions carried to approve the meeting summary from February 10–11, 2005, and May 12–13, 2005.	The TLDC reviewed the summary from the TLDC meeting on February 10–11, 2005, in Denver: – Ms. Holt requested the following change: On page 7, change the statement from "taking information from the research" to "taking information from the scientific literature". – Ms. Smith moved to adopt the TLDC meeting summary of February 10 and 11. Mr. Freddie seconded the motion. – The motion carried to approve the meeting summary with two abstentions from the California and Bemidji Areas. The TLDC reviewed the summary from the TLDC meeting on May 12–13, 2005, in Portland: – Ms. Smith requested that a section for excused TLDC members be added and that she be included in this section. – Ms. Holt moved to adopt the TLDC meeting summary of May 12 and 13. Ms. Smith seconded the motion. – The motion carried to approve the meeting summary with two abstentions from the California and Bemidji Areas. **Break**	Transcript Cross-Reference: Pages 65
Finalize the TLDC Charter Summary of discussion from Day One Quorum, proxy, and TLDC policies and procedures	**Meeting called to order at 1:35 p.m.** Mr. Rolin summarized the charter recommendations made during Day One: – TLDC will submit the charter to Dr. Grim in letter form. – Under membership composition, Mr. Rolin recommended that mention of the NCAI and NIHB be separated to easily identify the five national organizations. – The TLDC recommended to keep the membership rotation and leadership sections as presented in the draft charter. Ms. Smith noted that the TLDC should not need to include leadership term limits in their charter unless Dr. Grim is asking all advisory groups to do so. – The TLDC will not include sections 10 and 11 in the charter letter. Quorum, proxy, and TLDC policies and procedures: – The NIHB will develop policies and procedures for the TLDC to review during the November TLDC meeting. This document will cover topics such as the quorum, proxy voting (when both the representative and alternate are absent from the meeting), appointment procedures, and how to handle numerous unexcused absences. – Mr. Rolin noted that the issues of the quorum and proxy voting did not	Transcript Cross-Reference: Pages 66–70 NIHB will develop policies and procedures for the TLDC prior to the November meeting

Subject	Discussion	Action
Motion carried to adopt the TLDC charter	need to be included in the charter because Dr. Grim did not include these issues in his original letter to the TLDC. Ms. Nelson and Mr. Swain noted that they felt that including these issues in the charter was important. Ms. Smith, Ms. Holt, and Mr. Rolin noted that these issues could be addressed in the policies and procedures, as well as verbally with Dr. Grim. Motion to adopt the TLDC charter: – Ms. Nelson moved to adopt the TLDC charter. Ms. Abramson seconded the motion. – After some discussion, Ms. Holt called the question on the motion. – The motion carried to adopt the TLDC charter with one abstention from the Phoenix Area.	
Legislative Update Update on the reauthorization of the IHCIA	Rhonda Harjo from the Senate Indian Affairs Committee provided an update on the reauthorization of the IHCIA: – Ms. Harjo noted that the reauthorization of the IHCIA is a top priority for Senator McCain, chair of the Senate Indian Affairs Committee. – The Senate Indian Affairs Committee recently completed eight months of intensive negotiation on the IHCIA and narrowed down the remaining issues. – A joint hearing on the IHCIA with the Indian Affairs and the Health, Education, Labor, and Pensions committees was held on July 14, 2005. – Ms. Harjo and her colleagues started the negotiations and discussions with the Administration in August 2005. The Administration raised a number of issues, and they reserve the right to raise other issues in the future. Ms. Harjo is in the process of writing a report for the National Steering Committee so that they can respond to certain issues. – CMS provided technical assistance and language for the IHCIA and has supported the IHCIA as good policy, which has helped with obtaining support from the Finance Committee. – The goal for the rest of this year is to complete negotiations on the last remaining issues, mark up the bill, and get it passed in the Senate. – Ms. Holt asked Ms. Harjo about Secretary Leavitt's position. Ms. Harjo responded that Dr. Grim is trying to meet with Secretary Leavitt to discuss the IHCIA. Mr. Rolin noted that Secretary Leavitt attended the 50th anniversary of the IHS and said that he was interested in and wanted to follow through with the reauthorization. – Dr. Acton asked about the status of the Area diabetes consultants in the new IHCIA. Ms. Harjo reported that the issue of the Area diabetes consultants have been included in the IHS testimony, but has not yet been resolved. The TLDC recommended that the IHCIA include language that each Area is required to have an Area diabetes consultant.	Transcript Cross-Reference: Pages 70–75 The TLDC recommended that the IHCIA include language that each Area is required to have an Area diabetes consultant.

Subject	Discussion	Action
Update from the NIHB	Stacy Bohlen, deputy director of the NIHB, provided an update on the NIHB's role in the reauthorization of the IHCIA: – The NIHB has created the National Coalition for the IHCIA Reauthorization to encourage all of the Tribes that have legislative professionals in Washington, DC, to work together and make the reauthorization of the IHCIA a consolidated effort. – The coalition and the National Steering Committee hosted a briefing for Hill staff on July 11, 2005, and a press conference on July 14, 2005. – The coalition is also starting a national grass roots letter writing campaign to Congress. The campaign will address the reauthorization of the IHCIA and why it is critical. – Ms. Holt noted that the National Gaming Association held their legislative summit in July 2005. Senator McCain, Congressman Pombo, and other Senators and Congressmen came before the Tribal leaders and committed their support to the IHCIA reauthorization.	
Meeting wrap-up	Meeting wrap-up: – Ms. Montiel reported that the Phoenix Area will hold a three-day conference on diabetes November 14–16, 2005, and a diabetes training September 14–16, 2005. – The next TLDC meeting will be November 8–9, 2005, in Albuquerque. **Meeting adjourned at 2:49 p.m.**	